

## Complete Summary

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### GUIDELINE TITLE

Helping families raise children with special health care needs at home.

### BIBLIOGRAPHIC SOURCE(S)

Johnson CP, Kastner TA. Helping families raise children with special health care needs at home. Pediatrics 2005 Feb;115(2):507-11. [16 references] [PubMed](#)

### GUIDELINE STATUS

This is the current release of the guideline.

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## SCOPE

### DISEASE/CONDITION(S)

All pediatric illnesses and disabilities that result in special health care needs

### GUIDELINE CATEGORY

Management

### CLINICAL SPECIALTY

Family Practice  
Pediatrics

## INTENDED USERS

Physicians

## GUIDELINE OBJECTIVE(S)

To educate physicians on the philosophy of providing a permanent family environment (permanency planning) for all children, including those with special health care needs, and the importance of adequate and accessible community services to support and maintain the well-being of all family members

## TARGET POPULATION

Children, including infants, children, adolescents, and young adults up to 21 years of age

## INTERVENTIONS AND PRACTICES CONSIDERED

1. Permanency planning (permanent family environment for children with special needs)
2. Family support services including child care, respite, transportation, home modifications, durable medical equipment, behavior-management training, crisis intervention, faith-based services, assistance with transition to adult group homes
3. Additional parenting models
4. Out-of-home placement
5. Congregate care
6. Education and training of care providers
7. Physician advocacy

## MAJOR OUTCOMES CONSIDERED

- Family function over time (e.g., degree of family stress)
- Prevention out of home placement

## METHODOLOGY

### METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)  
Hand-searches of Published Literature (Secondary Sources)  
Searches of Electronic Databases  
Searches of Patient Registry Data  
Searches of Unpublished Data

### DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Not stated

#### NUMBER OF SOURCE DOCUMENTS

Not stated

#### METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Not stated

#### RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

#### METHODS USED TO ANALYZE THE EVIDENCE

Review

#### DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

#### METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

#### DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

#### RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

#### COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

#### METHOD OF GUIDELINE VALIDATION

Not stated

#### DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Not applicable

## RECOMMENDATIONS

### MAJOR RECOMMENDATIONS

#### Summary

To support and achieve Healthy People 2010 objective 6-7 (reduce the number of people with disabilities in congregate care facilities, consistent with permanency-planning principles, to 0 by 2010), pediatricians should work closely with biological families to identify local resources that can assist them in caring for their child with special health care needs to prevent out-of-home placement. If, however, the family considers out-of-home placement, the pediatrician should be knowledgeable of and be able to recommend other alternatives and supports and convey this information to the family to reinforce the principles of permanency planning and achieve and sustain an optimal nurturing environment for the child.

#### Considerations for Pediatricians

1. The goal of the medical home is consistent with Healthy People 2010 objectives and includes the provision of community-based, culturally effective, coordinated, and comprehensive care for children with special health care needs and their families.
2. The ongoing assessment of children with special health care needs ideally is family-centered, focusing on the child's quality-of-life goals as envisioned by the family. Ultimately, assessments will focus on the child as he or she matures into adolescence and adulthood and prepares for transition to adult living settings.
3. Throughout the ongoing care of the child, the pediatrician is encouraged to support the tenets of permanency planning. Permanency planning is the philosophy and practice of securing for children with special health care needs permanent family placement and ongoing relationships with caring adults. Permanency planning emphasizes the use of supports necessary to enable a child to be raised in a home, focuses on promoting a sense of belonging, and is evaluated according to the ability of the setting to promote ongoing secure relationships.
4. The pediatrician is encouraged to address the child's need for and the availability of an appropriate education, including later transition services. If the child is not being served appropriately by the local school system, physician advocacy may be necessary to both obtain the needed services and decrease the burden on parents in their own efforts to secure them.
5. The pediatrician is encouraged to address the parents' need for and ability to access and obtain family-support services, including faith-based services. If parents are in need of family-support services but have not been successful in accessing them, the pediatrician may advocate on behalf of the family through referral to social service agencies, which are usually housed in state agencies (i.e., state departments of health, human services, mental retardation and/or disability, or education).
6. Pediatricians are encouraged to advocate for the most reasonable and appropriate supports and services. The measure of what is reasonable and appropriate should always be in the best interest of the child. If, after careful consideration, the family determines that congregate care is the only available option, it should be considered a temporary placement followed by

- reunification or an in-home alternative-care option whenever possible. Pediatricians also are encouraged to help adolescents prepare for transition to adulthood and advocate for self-determination as some adults may choose to pool resources and share attendant care in group home settings.
7. Pediatricians, especially those in states that have not yet accessed waiver services through the Tax Equity and Fiscal Responsibility Act (Katie Beckett Act), can be effective advocates for increased funding for family supports by working collaboratively with legislators to access and match federal resources. The public policy link on the Family Voices Web site (<http://www.familyvoices.org/policy.htm>) is helpful in providing the clinician with information about important proposals to Congress that relate to permanency planning and family supports.
  8. Pediatricians can be helpful in identifying possible alternative families. Good prospects are families already caring for a child with special health care needs, foster parents of typically developing children, and parents who work in the health care fields. Pediatricians can also be helpful in educating and training care providers.

#### CLINICAL ALGORITHM(S)

None provided

### EVIDENCE SUPPORTING THE RECOMMENDATIONS

#### TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is not specifically stated for each recommendation.

### BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

#### POTENTIAL BENEFITS

Provision of comprehensive and effective special health care requirements for children and the families caring for them

#### POTENTIAL HARMS

Not stated

### QUALIFYING STATEMENTS

#### QUALIFYING STATEMENTS

The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

## IMPLEMENTATION OF THE GUIDELINE

### DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

## INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

### IOM CARE NEED

Living with Illness

### IOM DOMAIN

Effectiveness  
Patient-centeredness

## IDENTIFYING INFORMATION AND AVAILABILITY

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### ADAPTATION

Not applicable: The guideline was not adapted from another source.

### DATE RELEASED

2005 Feb

### GUIDELINE DEVELOPER(S)

American Academy of Pediatrics - Medical Specialty Society

### SOURCE(S) OF FUNDING

American Academy of Pediatrics

### GUIDELINE COMMITTEE

Committee on Children With Disabilities

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#### FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

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#### GUIDELINE AVAILABILITY

Electronic copies: Available from the [American Academy of Pediatrics \(AAP\) Policy Web site](#).

Print copies: Available from American Academy of Pediatrics, 141 Northwest Point Blvd., P.O. Box 927, Elk Grove Village, IL 60009-0927.

#### AVAILABILITY OF COMPANION DOCUMENTS

None available

#### PATIENT RESOURCES

None available

#### NGC STATUS

This NGC summary was completed by ECRI on February 23, 2005. The information was verified by the guideline developer on May 5, 2005.

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